

DOCUMENT RESUME

ED 307 748

EC 220 253

AUTHOR Knoll, James; Racino, Julie Ann
TITLE Community Supports for People Labeled by Both the
Mental Retardation and the Mental Health Systems.
INSTITUTION Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY National Inst. on Disability and Rehabilitation
Research (ED/OSERS), Washington, DC.
PUB DATE 88
CONTRACT 300-85-0076
GRANT G0085C03503
NOTE 33p.
AVAILABLE FROM Syracuse University, Center on Human Policy, Research
and Training Center on Community Integration, 724
Comstock Ave., Syracuse, NY 13244-4230 (\$2.30).
PUB TYPE Viewpoints (120)
EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Adults; Behavior Disorders; Behavior Modification;
*Community Programs; Delivery Systems; *Emotional
Disturbances; Holistic Approach; Individualized
Programs; Interpersonal Relationship; Mental
Disorders; *Mental Retardation; *Multiple
Disabilities; *Normalization (Handicapped); Social
Integration; Theories

ABSTRACT

The paper addresses issues in providing community services for people with both mental retardation and emotional or behavioral disorders. First, it explores the meaning often found at the root of the often elusive definition of dual diagnosis concluding that this has become a catch-all category for people who present existing service systems with the greatest challenges. Then it examines two, often conflicting, theoretical perspectives (the holistic versus the traditional behavioral perspective) underlying the widely varied approaches to services for these people. Finally, the crucial characteristics of integrated community-based services are discussed. These include small size, choice in roommates, functional programming, individualized planning, staff availability and flexibility, a long-term commitment, personalized service coordination, respect for autonomy and choices, individually tailored supports, flexible supports, and team support. Finally, the critical importance of forging enduring human relationships is stressed.

(DB)

* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *

ED307748

EC 226253

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

☒ This document has been reproduced as
received from the person or organization
originating it.

☐ Minor changes have been made to improve
reproduction quality.

• Points of view or opinions stated in this docu-
ment do not necessarily represent official
OERI position or policy.

Center on Human Policy

COMMUNITY SUPPORTS FOR PEOPLE
LABELED BY BOTH THE MENTAL
RETARDATION AND THE MENTAL
HEALTH SYSTEMS

BEST COPY AVAILABLE

2

"PERMISSION TO REPRODUCE THIS
MATERIAL HAS BEEN GRANTED BY

Steven Taylor

TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)."

COMMUNITY SUPPORTS FOR PEOPLE LABELED BY BOTH
THE MENTAL RETARDATION AND THE MENTAL HEALTH SYSTEMS

by

James Knoll and Julie Ann Racino

1988

RUNNING HEAD: COMMUNITY SUPPORTS

The authors would like to thank Steve Taylor, Gunnar Dybwad, Doug Biklen, Michael Smull, Bonnie Shoultz, Terri Johnson, and Hank Bersani for their contributions to this article. This report was partially supported by contract nos. 300-85-0076 and G0085C3503 with the U. S. Department of Education, National Institute on Disability Research and Rehabilitation. The opinions expressed herein are solely those of the authors and no endorsement of the U. S. Department of Education should be inferred.

COMMUNITY SUPPORTS FOR PEOPLE LABELED BY BOTH
THE MENTAL RETARDATION AND THE MENTAL HEALTH SYSTEMS

"You know, I think everyone should live in the community-- but I'm not sure how you can do it for people with really serious behavior problems or significant mental health needs."

This regional administrator is not alone in his concern. As the staff of the Community Integration Project and The Research and Training Center on Community Integration interviewed administrators and service providers from around the country, many of them echoed his opinion. Often people who have been given some variant of the label "dually diagnosed" are identified as the most difficult people to support in the community. The issues presented by these individuals have led to the development of an incredible range of services and supports. On the one hand these include traditional institutions and segregated community facilities:

- * Private institutions, taking referrals from throughout the country, which use an intensive program of behavioral techniques, including very noxious aversive interventions, to modify behavior;
- * Semi-autonomous units at state psychiatric centers which are administered by the state mental retardation department for the treatment of people with dual diagnosis; and

- * Specialized group homes for 6 or 8 people with very "enriched" staffing patterns and a highly structured daily routine where data is collected on literally every minute of the residents' day.

On the other hand there are numerous examples of services where people who have the same level of disability are integrated into the community:

- * An apartment that is shared by two men in their twenties, one of whom is paid as a "service provider" while the other is a man who was in shackles when he moved out of the institution where he had spent most of his life;
- * A home where a young woman in her twenties, who was previously in a state mental hospital and in a locked behavioral unit in a state mental retardation institution, now lives with a couple she has known for many years and their two children;
- * A home where a young woman is temporarily supported by a total of 15 nondisabled people, including 4 full time staff, so there will be two people with her at all times; and
- * A foster home where the foster mother speaks about the desire to adopt her adolescent foster child, regardless of the child's outbursts of aggressive and self-abusive behavior.

These vignettes are not intended to describe a continuum of residential options available to people with a dual diagnosis. On the contrary, this list calls into question the logic of the continuum of services (Taylor, in press). The more restrictive

examples cited above (e.g., institutions) are frequently offered as the end of the continuum, the last resort for people who "cannot make it in the community" (i.e., they just do not "fit" into one of the spots available in the service system). Yet, the individualized community living situations (e.g., supports in a home or apartment) undercut the continuum concept by demonstrating that people with the same characteristics as those who have been institutionalized can be supported in typical homes and apartments.

In this paper we will explore the meaning that is usually found at the root of the often elusive definition of dual diagnosis. We will then briefly examine two, often conflicting, theoretical perspectives which underlie the widely varied approaches to services for these people. Finally, we will discuss the crucial characteristics of the integrated community-based services which are supporting people with a dual diagnosis.

What Does the Label "Dual Diagnosis" Mean?

Advocates of community integration continually run up against various versions of the following argument: "Well, that's fine for the people you are describing, but it will never work for the people I know. We're just not talking about the same people." To confront this position we asked service providers from around the country, who were nominated because of their commitment to supporting people with severe disabilities in the community, to specifically describe individuals whom other agencies had identified as "unable to make it in the community"

(Community Integration Project, 1986; Taylor, Racino, Knoll, & Lutfiyya, 1987; See also Note 1). While the providers we interviewed did not use the term, many of the people who they described in response to this question would be labeled with a dual diagnosis in many service settings.

The label of dual diagnosis has a myriad of meanings both in the literature and in popular usage. Taken literally, the term simply means a person having two diagnostic labels. For example, the term may refer to people who have both a mental health and an alcoholism label, or who are both blind and hearing impaired, or who have both a mental health and mental retardation label. Used alone the term dual diagnosis provides no information even about the types of labels a person may have received.

Here, our primary focus is on people who have been labeled by both the mental retardation and the mental health systems. In discussing this issue we wish to stress that this is not an acceptance or endorsement of this system of classification (Szymanski & Grossman, 1984); rather this paper reflects our belief and the testimony of service providers that people labeled by the mental health and mental retardation systems can be supported in integrated ways in the community.

Even with this narrower focus, the term dual diagnosis is still applied to a wide range of people with diverse needs. It can include people labeled mildly mentally retarded who are being treated by a therapist, counselor, psychologist or psychiatrist, who have been involved with the criminal justice system, who are "non-compliant," who have a history of "running away," or who

have been accused of child abuse, sexual misconduct, or setting fires. When applied to people with more severe retardation and/or multiple disabilities, dual diagnosis usually means that they have shown some form of "challenging" behavior that a psychologist or psychiatrist has noted as "symptomatic of an underlying disturbance." This may include apparently unprovoked aggression or self-abusive behavior.

A number of studies (Menolascino & Stark, 1984; Szymanski & Tanquay, 1980) have indicated that over 25% of people with mental retardation have co-existing mental health problems. From one perspective, these figures have enabled some of the leading authorities in the field to help people with mental retardation gain access to community mental health services. From another perspective, a case could be made that the apparently high level of mental health issues in people with mental retardation may simply be an artifact of their degree of involvement in the human service system. In other words, if a person is labeled as mentally retarded he or she may have a much greater involvement with professional clinicians than the average nondisabled person. Hence there could exist a much greater likelihood that something that typically might be recognized by family, friends, and neighbors as a personality quirk, "a rough time," "feeling down," or "being under a lot of pressure" will be recognized by a professional and duly noted with its official clinical classification. This view is consistent with Merke and Wersing's 1984 study that found that the majority of these diagnoses as defined by the American Psychological Association (1980) fall

into the categories of personality disorders which tend to respond best to environmental adjustments.

Finally, for some individuals the label of a dual diagnosis is solely the result of the paper trail that follows everyone who comes into contact with human services. In other words, it is something that is in the person's file and follows him or her through life. It may be a "misdiagnosis" made by a clinician early in the person's life (e.g., the various diagnostic labels that are frequently found in the case records of individuals who are eventually labeled as being autistic). Or, it may be the artifact of a designation required to enter a program or receive specific services at some point in the person's life. Like so many other labels, a dual diagnosis really tells us very little about the people who are stuck with that designation.

So then, who are we talking about? When we read the literature and talk to service providers, what are the consistent characteristics that link this diverse group of people who are labeled with a dual diagnosis? We feel that a critical analysis of this label leads to the conclusion that it is the catch-all category for the people who present the existing service systems with the greatest challenges (cf. Holmes, n.d.). In another time and another place, many of these people have been called the "incorrigibles," the "chronics," or the "hopeless cases." Today people with dual diagnosis are some of the same people who many regard as being "at risk of requiring more restrictive care or loss of opportunities for employment, mainstream schooling, or other community participation" (Holmes, n.d., conclusions and

recommendations, p. 1).

Before we examine some of the crucial elements of services which are successfully supporting some of the hardest to serve people in the community, there is a broader theoretical issue which needs to be addressed. As we reviewed programs and spoke with service providers we noticed that their underlying theoretical perspective seemed to have major implications for the quality of life of the people in the program. The answer to crucial question, "Where's the problem?" seems to lie at the heart of the two divergent theoretical points of view, which appear to dominate the field of developmental disabilities.

A Holistic Versus A Traditional Behavioral Perspective

As we compared the recent Holmes report (n.d.) on the state of the art in services for people with dual diagnosis and the programs that emerged from our interviews we were struck by some major differences. The programs that Holmes describes tend to be relatively large, not located in the community, and emphasize intensive behavioral interventions. The basic orientation in these programs seems to be on removing the person to a specialized treatment environment and changing the problem behavior so the individual can return to the community or, more typically to a "less restrictive" group home or other community facility. The programs we identified are generally very small, located in the community (in apartments or existing housing), and focused on enhancing overall quality of life. It seemed that there was something more at work here than just a difference in

the location of services. We realized that we were witnessing the programmatic expression of two fundamentally different perspectives on human behavior.

Traditional Behavioral Perspective

For the most part the programs listed in the Holmes study reflect a relatively traditional behavioral approach. Anyone educated in human services during the last 25 years is familiar with the basic tenets of behaviorism: Behavior occurs because it is reinforced; change the conditions--eliminate or refocus the reinforcement--and you can change the behavior. This basic insight and its implications have radically transformed the lives of many people with severe disabilities because it provided human service practitioners with an alternative to mere custodial care. As experience was gained in using this approach clinicians realized that with the right interventions they were able to manage or control almost any behavior. The behavior specialist became a surgeon of human behavior, "Show me a maladaptive behavior and I can cut it out." Usually, this attitude was guided by the best of human motivations: to improve the quality of life available to people by eliminating those actions that tended to alienate them from other people. Unfortunately this technique was also frequently used for the primary purpose of facilitating the management of groups of people in large facilities.

Many of the programs listed by Holmes are examples of this approach. The clinician in these settings identifies the

behavior that interferes with a person living in a community setting and then develops an intervention to remove that behavior from her repertoire. The person goes into the "behavioral hospital," the specialized setting to have these treatments applied. Afterwards he or she can then move to a less specialized setting where the treatment can be prescriptively reapplied if the symptoms reappear. Unfortunately, as people like Lovett (1985) have shown, this is a basic misdirection of behaviorism since it ignores the total context of behavior and usually does not recognize or respond to the point of view of the "client." Often little, if any, reflection is given to the complex network factors which influence the behaviors. The restrictive, unstimulating, and frequently dehumanizing situations that society has forced upon people with severe disabilities are seldom considered the "cause of the problem."

The community programs we interviewed and visited felt "You can't really teach people how to live in a neighborhood and get along with others by putting them in a special setting from which they can graduate back into the community." And, in discussing issues of behavior management--and they all use behavioral techniques and behavioral consultants--these providers were quick to assert their belief that "undesirable behavior" had a functional meaning. In other words, they felt that even the most troublesome behavior served a function for the person who was doing it even if the service provider did not initially understand its purpose. This meant that to deal with "problem behaviors" they had to find a functional adaptive behavior they

could teach the person which would fulfill that same need. Lovett and others contend that this type of orientation is more reflective of behaviorism's promise. This perspective on human behavior is sometimes called an "ecological" or "holistic" approach.

The Holistic Perspective

The holistic approach examines the role people play in their environment, the match between the individual and the demands of the environment, and the complex interplay of forces which influence individual behavior. Rather than seeing behavior as caused either by some internal drive or the mechanistic response to an external stimuli, the initial formulators of what has become the holistic perspective took their lead from Kurt Lewin's classic statement that behavior is a function of the interaction between a person and the environment ($B=f(PE)$, Lewin, 1935, p. 73). In the years immediately after World War II a group of researchers used Lewin's earlier work and undertook a social-psychological examination of the lives of people with physical disabilities (Dembo, Leviton, & Wright, 1956). This work led to the conclusion that most of the limitations on people with disabilities are imposed by society rather than being intrinsic to an individual's functional deficit. Bronfenbrenner (1979) and his colleagues further developed this theory of behavior by highlighting the need to see individual actions and the definition of that behavior as the product of a series of complex interactions. From this perspective all of the elements which

contribute to a behavior are not immediately present in the setting where it occurs.

William Rhodes (1967) was the first to describe the value of a holistic perspective for practitioners in special education and related disciplines. Speaking specifically of students labeled emotionally disturbed, he pointed out that educators had come to see disturbance as something residing in the student. Hence, their interventions were exclusively geared toward remediating the flaw within the person. As a more practical educational alternative, he proposed a holistic view that focused on the interactive nature of the problem behavior and saw disturbance as residing in the tension between the individual and the demands of the environment.

Subsequently, a number of authors have explored the theoretical and programmatic implications of a holistic analysis of people with disabilities in our society (e.g., Algozzine, 1977; Apter, 1982; Hobbs, 1975, 1980; Swap, 1974, 1978). Following Rhodes' lead most of these authors have focused almost exclusively on the need to see what is called "emotional disturbance" as resulting "from a discrepancy between...skills and abilities and the demands or expectations of...(the) environment" (Apter, 1982, p. 2). Similarly, ecological theory has been used as a model for the most innovative programs for individuals with severe disabilities (Brinker, 1985; Brown, Falvey, Baumgart, Pumpian, Schroeder, & Gruenewald, 1980) and as a framework for viewing issues in community services for people with disabilities (Hitzing, 1987; Lovett, 1985; Smull, 1987).

From this broader view of disability there are three possible areas for intervention: a) change the person, b) change the environment, or c) change societal attitudes and expectations. Many of our efforts in the past have focused on changing the person. Today, we are looking much more at ways to change the environment and attitudes. Finally, a major implication of a holistic orientation is that we give up searching for a magic answer to the problems of disabled people. Instead, we must begin to think about problems in the system and increase our understanding of the interaction between the individual and the environment (Apter, 1982).

Forging the Community Connection

In our conversations with service providers who are supporting people labeled by the mental retardation and mental health systems in the community, we tried to elicit those factors that differentiate their programs from traditional service agencies. What emerged from this was a clearer understanding of some fundamental issues in human services. It seems that as we narrow our focus to the people who are most frequently identified as those "who can never make it in the community" we are forced to examine the fundamental question of what it is that HUMAN SERVICES are all about. For this reason, some central themes emerged in our interviews which have applicability in any agency or setting which is concerned with assisting people with severe disabilities to be part of the community. From the point of view of the people we interviewed the central issues in the field of

community support seem to be commitment, individualization, flexible supports, and human relationships (Taylor, Racino, Knoll, and Lutfiyya, 1987).

Commitment

In the programs we examined the holistic perspective was often an "unconscious" frame of reference which found its strongest expression in a clear and uncompromising commitment to the community as the place where people should live. As one service provider put it "You don't try to get them ready for the community; you just start in the community." For the providers we interviewed it was incomprehensible to think of "sending someone back" to an institutional setting. They did not see the community as some sort of magic cure for the many problems in the lives of the people they served, but it was an accepted fact of life that everyone had a right to live in the community. Their job as a community service provider was to help resolve the issues in an individual's life within the community.

It is also noteworthy that this perspective and commitment found expression in the words that providers used to describe the situations in which people lived. We rarely heard the word "facility" or "program" or even "group home" or "home-like environment." We were continually told about people--regardless of the level of support they needed--and their HOMES. Much of what came through in our conversation was the belief that people needed a home, a place of their own where they exercised control. The stories about people almost universally told of the

sudden emergence of skills and the disappearance of inappropriate behavior as a sense of security and personal ownership developed. Home and community may not be a magic cure, but the testimonials are quite powerful.

On a less dramatic level, here are some of the ways that a belief in the power of environments to shape behavior and a commitment to community living played out in the lives of the "hardest to serve" people in a number of places.

- * One agency in the Northeast finds competitive community jobs for people with some very unusual behaviors by carefully looking at what the person does and then finding jobs where the behavior would be the least obtrusive. In other words an environment is found which matches with the person, rather than first requiring that the person fit the environment.
- * A program in the rural Mid-West supports a person who spent a great deal of his life in restraints in an institution in an apartment with a single roommate/support person. When this placement almost collapsed the agency took a careful look at what it was doing and identified a need for an improved system of support for its live-in support people. The system had to change to accommodate the needs of individuals, not vice versa.
- * In Oshkosh, Wisconsin flexibility in funding at the county level enabled two individuals to move to a smaller group setting, rather than being sent out of their community to a "secure" setting. Supposedly they presented too many

problem behaviors to live in the community. However, because of an ability to respond to this crisis, these two men were able to remain near home, where they are now "making it."

- * In Michigan, the Supported Independence Program maintains people in their own homes. An awareness of the numerous problems created when people with behavioral problems are grouped together has led the staff to view this approach as well suited for these individuals. "Behaviorally troubled clients may receive higher quality treatment in a smaller setting. With less competition, ..., the participants may feel less need to act out for attention" (Taylor, 1985, p. 27).

Individualization

The last example points out one of the major contradictions in human services: A rhetoric of individualized services but an emphasis on congregating relatively large groups of people. There are a number of factors that service providers pointed to as ways of structuring living situations so they help rather than hinder a truly individualized approach to services.

1) Small Size. Service providers value small size because they say people feel more secure since they have fewer people to deal with and they have a greater sense of control over their life space. From the perspective of the direct service worker small size is valuable because it enables them to really get to know people and it removes the need to worry about "managing a

facility" that is often associated with larger settings. The general consensus of these providers seemed to be that as the problems associated with supporting a person increased, the need for the person to live with a few people or even alone also increased.

2) Choice in Roommates. Most agencies felt that the nature of the grouping was as important as size of the group. They universally testified to the problems with the common practice of creating a specialized setting where all of the "most difficult" people were grouped. In such settings the competing needs of the residents are often more than the staff are able to meet since they must almost exclusively devote their attention to managing the group. A number of the providers mentioned the importance of people having a choice about with whom they would live. Matching people based on characteristics other than similar disability (e.g., common interests, desire to live together) seems to be crucial.

3) Functional Programming. In general, service providers warned against having the demands of the facility or the nature of the program dictate the "individualized" goals for the residents. The concentration on programming should be on developing the skills that are required by the demands of each individual's unique life situation. Service providers who have fully adopted this approach see the mutual interdependence of housemates and the demands of each individual's daily routine dictating the components of their "functional" program.

In a similar vein, this truly functional approach is seen as

the positive alternative to behavioral interventions which solely attempt to control or eliminate behavior. Essentially service providers and behavioral consultants look to a person's life in an effort to understand his or her behavior. They attempt to identify new, adaptive functional skills that satisfy the same needs as a problem behavior, while also serving a real purpose in daily life. Admittedly, all behaviorists will say this is what they do. The difference lies in the fact that most traditional behaviorists take a very narrow focus as they identify the antecedents and consequences of a behavior. From a holistic perspective, the full context of an individual's life is considered.

4) Individualized Planning. A key element in individualized service is a planning process which brings together all of the people whose cooperation is essential for assuring the future quality of life of the individual of concern. O'Brien, (1987) offers a forum for such an approach to planning which he calls "Personal Futures Planning." Some service providers who have implemented this approach have found that it is a particularly useful tool when the individual of concern is someone who offers the service system a lot of challenges. As O'Brien describes it the person's life is reviewed from the five perspectives of 1) community presence, 2) choice, 3) competence, 4) respect, and 5) community participation. It is his thesis that these five elements are the way most people define the quality of their lives. Within the framework of these themes the planning process then revolves around eight questions about the person's life:

- 1) What is the quality of the focal person's present life experience?
- 2) What is changing for the person or in the surrounding environment that is likely to influence the quality of the focal person's life?
- 3) What are the most important threats and opportunities to better life experience for the focal person?
- 4) What is the image of a desirable future for the focal person?
- 5) What are the most critical barriers to our moving toward the desirable future?
- 6) How will we most effectively manage these critical barriers and move toward the future we've defined?
- 7) What are the next steps?
- 8) Based on our discussions, do we want to make any statements about necessary changes in the capabilities of the service system?

The end result of this is a shared vision of the unique situation of a specific individual and a plan of action for moving toward that goal. The description of the meeting concludes with a reminder that the nature of the supports available to follow up on the plan will determine if this valuable process really does make a difference.

Flexible and Individualized Supports

A manual published by the Options in Community Living program in Madison, Wisconsin provides (Johnson, 1985) a useful

summary of some of the characteristics that mark some of the most effective community support agencies. The following descriptions build on Options listing of some of the elements that are essential considerations when an agency focuses on supporting individuals with disabilities in the community.

1) Staff Availability and Flexibility. Frequently the people who fall into the category of "the most challenging" need and want regular direct contact with support people, although often under conditions that they choose. This contact may simply be for companionship and emotional support. Option's experience shows that if staff is not readily accessible, people may invent problems or bring on crises just to make sure they get contact. This means that in some situations, it may be important for people to be present and available even if the person needs little support in the routines of daily life. This may mean dropping in and answering phone calls at unusual hours. It may also mean being in touch with potential problems in order to defuse them before they escalate (e.g., problems with neighbors).

2) A Long-term Commitment. Some people may need reassurance that there are individuals who have made a long-term commitment to supporting them. The people that work with them and the agency has to be willing to stick with them in good times and bad, during periods of erratic behavior, and when no progress is being made. This means that involvement does not end when a crisis is over, or if a person is uncooperative, or if they throw the staff out of the house. There is an ongoing commitment to the person.

3) Personalized Service Coordination. People who present the greatest difficulties to service providers are also likely to be the ones with the greatest number of agencies involved in their lives. They may have been shuffled around by everyone in the service system, because no one was willing to make a commitment to provide them with what they need. This means that an agency which decides to accept a long term responsibility to a person has to work formally and informally with other agencies to prod them to work out ways to adjust their policies to meet the person's needs. This also means advocating for new and innovative services which meet the specific need of the individual and for collaboration which crosses over agency lines of responsibility.

4) Respect for Autonomy and Choices. In many cases some of the most challenging people are also the people who are the most capable of getting around the community on their own. Like most of us they place a high value on their freedom and resent efforts by outsiders to manage their lives. This very tension, between personal freedom and the demands of programs is often at the root of their history of failure in the service system. The other side of this battle for autonomy is that the individuals may display odd behaviors or exercise poor judgment that results in dangerous situations in the community. People with disabilities often have had few opportunities to experience making decisions, even small ones, throughout their lives. This means that staff members must know how to assist people in making real choices and to be comfortable with balancing the risks involved. Staff

members must also learn to determine how much intervention a person will tolerate and be able to break off when they see the person is reaching their limit.

5) Individually Tailored Supports. Supports must be developed to match the strengths and needs of the person and to build on natural community resources. The supports may include: 24 hour a day crisis intervention, back up for support staff (one phone call away), in-home behavioral consultants, regular respite, homemaking aides, in-home support staff, additional training for support staff in individual interventions, and the more typical supports of recreation, personal relationships, community memberships and meaningful work/education. Success in this area depends on the realization that the type and intensity of supports will vary for every person being served by an agency.

6) Flexible Supports. People change over time and the supports they need must adapt to match their changing life situation. For example, two roommates, who at one point enjoyed living together, may no longer wish to continue to do so. In another situation, the person may have experienced a death of a loved one and need additional supports for a period of time. The intensity and type of supports for each individual with a disability must adapt and change to conform to their ever changing life situation.

7) Team Support. It is important for support staff to feel that they, too, are supported. One way that agencies promote this support is through a team structure where several staff know the person and the home/job very well. Staff need colleagues to

turn to for new ideas and for encouragement to try different approaches. Supervisors have to let staff know that the work they are doing is important and that there are no "magic solutions" to the problems they must confront on a daily basis.

Human Relationships

Throughout our interviews and site visits, it was clear that good quality services to people with very "challenging" behaviors are particularly dependent on enduring human relationships. We want to focus momentarily on what that means for staff and for relationships with other community members.

In reaction to the clinical attitude that has marked the traditional approach to behavioral intervention, agencies that use a community focused holistic approach tend to emphasize connectedness over detachment. Certainly, service providers use the insights of behavior technology to help them in dealing with the myriad of problems in the lives of the people they support. But, most spoke of using "Gentle Teaching" (McGee, Menousek, & Hobbs, 1987) or some other nonaversive personalized translation of behaviorism (Lovett, 1985). Essentially these approaches are based on the principle that positive human interactions are the most powerful reinforcers for human beings. However, the experience of most people with behavioral problems has undercut this basic human value by denying it and substituting all manner of artificially contrived reinforcers. So, humanistic behaviorism seeks to re-establish the value of human presence and positive interactions. Clearly, the effectiveness of this

approach is based on the commitment and genuine concern of individual direct service workers and other people involved in the life of the person needing support.

Another major concern in programs and agencies which are supporting people who have traditionally pushed human services to the limit is how to get them out from under the system. This is not to say they want to "cut these people loose" to sink or swim on their own in the mainstream. As we noted above many of these agencies assume that they are making a long-term commitment to people to be there for them when they need support. But this commitment does not in any way replace the need for people to get connected with the community. The agency will be there to help, but the underlying belief is that real success is achieved when a person becomes an active participant in the community.

Being part of a community means that people have enduring relationships with people other than those paid to be with them. With real friendship comes natural systems of support that are often able to forestall or prevent relatively minor problems from becoming insurmountable difficulties which escalate into a crisis. Most people have these systems, but people who have been in the human service system have frequently had them subverted in favor of professional intervention. As we noted above the high prevalence of diagnosed mental health problems in people with mental retardation may partially be an artifact of this dependence on professionals instead of friends.

There is no question that the "methodology" for linking people, noted for their unique ability to alienate others, to the

community is the greatest challenge facing service providers. It is not the kind of thing that has traditionally been addressed in the course of professional preparation. Indeed, over involvement by professionals in this process might lead to the development of "friendship therapy." The best practices in this area seem to be marked by sensitivity and intuition. That is to say, the staff knows that forging this community connection is a priority. They talk and think about this issue in relation to the individuals they support. An attempt is made to provide opportunities for people to meet others and sometimes a staff person may try to help people over the initial introductory hurdles. Since relationships are a priority other programmatic considerations will be secondary. So in this age when so much emphasis is placed on management by objective and clearly defined goals, the goal which will make the greatest difference in the lives of people with disabilities is the one we are the least able to measure.

Conclusion

The intent of this paper is not to give the impression that the problems presented by people with a dual diagnosis are easily addressed. Some of these individuals truly do challenge service providers to live up to their rhetoric of individualized services and commitment to community living. What is clear is that if people are convinced that there is no alternative to the community and the service system is truly willing to meet the real needs of individuals in the community half the battle is

won. Then it is no longer just a question of deinstitutionalization or least restrictive environment or community integration. Rather it is human services returning to its basic roots, the coming together with a neighbor to help someone get through the crises in their lives. But as Gerald Provencal, Director of Macomb-Oakland region in Michigan, has said, "The answers are easy; the work is hard" (cited in Taylor, Racino, Knoll, & Lutfiyya, 1987, p. 47).

References

- Algozzine, B. (1977). The emotionally disturbed child: Disturbed or disturbing? Journal of Abnormal Child Psychology, 5, 205-11.
- American Psychiatric Association. (1980). Diagnostic and statistical manual of mental disorders (3rd ed.). Washington, DC: American Psychiatric Association.
- Apter, S. J. (1982). Troubled children, troubled systems. New York: Pergamon Press.
- Brinker, R. P. (1985). Curricula without recipes: A Challenge to teachers and a promise to severely mentally retarded students. In D. Bricker & J. Filler (Eds.), Severe mental retardation: From theory to practice (pp. 208-229). Reston, VA: Division on Mental Retardation of the Council for Exceptional Children.
- Bronfenbrenner, U. (1979). The ecology of human development. Cambridge, MA: Harvard University Press.
- Brown, L., Falvey, M., Baumgart, D., Pumpian, I., Schroeder, J., & Gruenewald, L. (1980). Strategies for teaching chronological age appropriate skills to adolescents and young adults severely handicapped students (Vol. 9). Madison, WI: Madison Metropolitan School District.
- Community Integration Project. (1986). Programs demonstrating model practices for integrating people with severe disabilities into the community. Syracuse, NY: Center on Human Policy, Syracuse University.

- Dembo, T., Leviton, G. L., & Wright, B. A. (1956). Adjustment to misfortune--a problem of social psychological rehabilitation. Artificial Limbs, 3, 4-62.
- Hitzing, W. (1987). Community living alternatives for persons with autism and related severe behavior problems. In D. J. Cohen & A. M. Donnellan (Eds.), Handbook of autism and pervasive developmental disorders. New York: Wiley.
- Hobbs, N. (1975). The future of children: categories, labels, and their consequences. San Francisco: Jossey-Bass.
- Hobbs, N. (1980). An ecologically oriented, service-based system for the classification of handicapped children. In S. Salzinger, J. Antrobus, & J. Glick (Eds.), The ecosystem of the "sick" child (pp. 271-290). New York: Academic Press.
- Holmes, P. A. (n.d.). Final report dual diagnosis program study: MR/MI state-of-the-art service delivery. Ypsilanti, MI: Department of Psychology, Eastern Michigan University.
- Johnson, T. Z. (1985) Belonging in the community. Madison, WI: Options in Community Living.
- Lewin, K. (1935). A dynamic theory of personality. New York: McGraw Hill.
- Lovett, H. (1985). Cognitive counseling and persons with special needs: Adapting behavior to the social context. New York: Praeger.

- McGee, J. J., Menousek, P. E., & Hobbs, D. (1987). In S. J. Taylor, D. Biklen, & J. Knoll (Eds.) Community integration for people with the most severe disabilities (pp.147-183). New York: Teachers College Press.
- Menolascino, F. J., & Stark, J. A. (1984). The handbook of mental illness in the mentally retarded. New York: Plenum.
- Merker, E. L., & Wernsing, D. H. (1984). Medical care of the deinstitutionalized mentally retarded. American Family Physician, 29 (2), 228-233.
- O'Brien, J. (1987). A guide to life-style planning. In G. T. Bellamy & B. Wilcox (Eds.), A comprehensive guide to the activities catalog: An alternative curriculum for youth and adults with severe disabilities (pp. 175-189). Baltimore. MD: Brookes.
- Reiss, Steven. (1987). Symposium Overview: Mental Health and Mental Retardation. Mental Retardation, 25 (6), 323-324.
- Rhodes, W. C. (1967). The disturbing child: A problem of ecological management. Exceptional Children, 33, 449-455.
- Smull, M. W. (1987). Systems issues in meeting the mental health needs of persons with mental retardation. In J. A. Stark, F. J. Menolascino, M. Albarelli, & V. Gray (Eds.), Mental retardation and mental health. New York: Springer Verlag.
- Swap, S. (1974). Disturbing classroom behavior: A developmental and ecological view. Exceptional Children, 41, 162-171.

- Swap, S. (1978). The ecological model of emotional disturbance in children: A status report and proposed synthesis. Behavioral Disorders, 3 (3), 156-186.
- Szymanski, L., & Grossman, H. (1984). Dual implications of "dual diagnosis". Mental Retardation, 22, 155-56.
- Szymanski, L., & Tanquay, P. (1980). Emotional disorders of mentally retarded persons. Baltimore, MD: University Park Press.
- Taylor, S. J. (1985). Site visit report: Macomb-Oakland Regional Center, Michigan. Syracuse NY: Community Integration Project, Center on Human Policy, Syracuse University.
- Taylor, S. J. (1988). Caught in the continuum: A critical analysis of the least restrictive environment. Journal of the Association for Persons with Severe Handicaps.
- Taylor, S. J., Racino, J., Knoll, J., & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse NY: Community Integration Project, Center on Human Policy, Syracuse University.

Notes

1. In addition to the general search for good practices in community integration which provided the basis for this report a second search was initiated that specifically requested information on best practices in service to people with a "dual diagnosis." This search was advertised in the Newsletters of the Association for Persons with Severe Handicaps and of the National Association For the Dually Diagnosed. It is, perhaps, noteworthy that with the single exception of the Holmes report (referenced above) this "specialized" search elicited no additional information. One possible reason for this lack of response may be that service providers who do the best job of supporting these people in the community do not think of the people they serve in terms of categories like "dual diagnosis."